

Running head: PEDIATRIC REGISTERED NURSES' PERCEPTIONS

1

Pediatric Registered Nurses' Perceptions of the Knowledge, Skills, Attitudes, and Resources
Required to Care for Adult Congenital Heart Disease Patients in a Pediatric Hospital

DNP Final Project

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Nursing Practice in
the Graduate School of The Ohio State University

By

Regina Prusinski, MSN, AC-PNP

Graduate Program in Nursing

The Ohio State University

2013

DNP Final Project Committee:

Gerene Bauldoff PhD, RN, FAAN, Advisor

Lissa Barker APRN, BC, FNP, FAANP, CHE, PhD

Linda Daley PhD, RN

Acknowledgments

I wanted to thank the Adult Congenital Heart team at Nationwide Children's Hospital and OSU. A particular thank you goes to Dr. Steven Crumb who started this work with APNs and co-moderated my focus group interviews. I would also like to thank Jenny and Renee Schnug, along with all of the adult congenital heart disease team, who both were kind enough to spend hours of their time showing me what they do every day.

The project itself could not have happened without the help of Melissa Leek, Tracy Heard, Susan Meyer, and all of the wonderful nursing staff on H4A, the cardiology floor at Nationwide Children's Hospital. The hardworking pediatric nurses of H4A open their hearts to their adult patients every day. I commend them and hope to be as caring in my own bedside manner.

Dedication

I wanted to say thank you to both my husband and mother who have supported me through this doctorate endeavor. My mom has backed my educational journey from the beginning. She probably had no idea how many graduations she would go to in one lifetime. A great sigh of relief may be heard from Mitchell Prusinski who has really only known me as a student and will finally be married to someone who doesn't have "homework."

Abstract

Background: Advances in medical treatment, management, diagnosis and surgical palliation have improved both the quality and longevity of children born with Congenital Heart Disease (CHD) (Berghammer, Dellborg, & Ekman, 2006; Dearani J. et al., 2007). As these patients' age, reach adulthood, there are no data or guidelines available to provide direction to the preparation of pediatric registered nurses to care for adult patients with complex congenital heart problems. Purpose: The purpose of this scholarly project is to describe the care experiences and the knowledge, skills and attitudes (KSA) identified by practicing registered nurses (RNs) in a pediatric hospital as requisite to caring for adult patients with CHD (ACHD). Methods: The project used focus group interviews with a population of Registered Nurses (RN) in The Heart Center at Nationwide Children's Hospital in Columbus, Ohio. This project mirrors a prior study focusing on pediatric acute care advanced practice nurses (APRN) caring for adult patients with congenital heart disease (ACHD) within the same setting (Crumb, 2012). Results: Pediatric bedside RNs caring for ACHD patients acknowledge perceptions of noncompliance on the part of some ACHD patients. Additional topics of concern are the chronic nature of the disease process and alterations in the ACHD patient in assuming independent adult roles. In describing KSA concepts that are essential for caring for the ACHD patient, the need of social work and the direct physician involvement, using direct and assertive communication techniques to promote rapport and review of the assessment differences between adult and pediatric patients in the congenital heart disease population were identified and described. Conclusions: The nursing staff caring for the ACHD patient wants to provide the best experience for their patients regardless of age. Descriptors to articulate care concepts of concern are limited. Communication skills to

deal with the adult patient as well as multi-disciplinary team utilization would be seen to improve the quality of care and better meet the needs of the ACHD patient. Additional recommendations would include development of appropriate adult resources, educational programming and evaluation of patient rules related to visitation. Addressing these concerns may help reduce nursing staff frustration and perceptions of lack of knowledge regarding care of the ACHD patient.

Chapter One: Nature of the Project

Introduction

Advances in medical treatment, management, diagnosis and surgical palliation have improved both the quality and length of life for many newborns with congenital diseases (Berghammer, Dellborg, & Ekman, 2006). Since the late 1930's, when surgery for ligation of the patent arterial duct was performed, to the 1990's when the arterial switch and Norwood palliation procedures were first successfully performed in the neonate, the surgical community has made great strides in improving the longevity and quality of life of the patient with CHD (Dearani, Connolly, Martinez, Fontanet, & Webb, 2007). The United States alone has an estimated population of 1 to 2.9 million adults with CHD. Almost half of the world's population of patients with CHD is now over the age of 18 years (Marelli, Mackie, Lonescu-Ittu, Rahme, & Pilote, 2007)

As these patients age, reach adulthood, and acquire new health problems they continue to be seen within pediatric medical settings for some, if not all, of their care. The need to transition adult patients into more appropriate care settings for lifelong follow-up is often recognized in the literature (Jalkut & Allen, 2009). However, despite the acknowledged need for transition to adult services, guidelines developed by the American College of Cardiology and the American Heart Association concur that adult patients with CHD need to be operated upon by cardiothoracic surgeons with training in congenital heart surgery; such surgeons are almost exclusively pediatric cardiothoracic surgeons (Dearani et al., 2007; Warnes et al., 2008). Wauthy, et al. (2011 p. 40) noted "it is mandatory that a single surgical team offer these young patients expertise both in congenital surgery of the newborn child and in the acquired pathology of the adult." This ultimately leads to the adult patient with CHD receiving their post-operative

care in the pediatric environment, pediatric intensive care unit (PICU) or pediatric cardiothoracic care unit (CTICU) with follow through on the pediatric cardiology floor or step-down unit.

The adult congenital cardiac patient population can be chronically ill and frequently seen throughout childhood at the pediatric heart center. Many of their disease processes are specific to their congenital heart problem, identified in the neonatal period, and require follow-up by pediatric specialists. Pediatric cardiothoracic surgeons and other pediatric interventionists perform the original palliative cardiac surgeries and continue to provide patients additional procedures such as valve replacements or cardiac catheterizations. As they reach adulthood, these patients may transition to an ACHD program where physicians trained to care for adult cardiac congenital patients follow them and refer them to appropriate adult services when needed. Even with this transition, some procedures or specific surgeries still may be done at pediatric facilities. This is the difference between this chronically ill adult patient population and other patients with similar congenital disease processes that follow them from childhood into adulthood such as patients with cystic fibrosis, sickle cell disease, phenylketonuria or cerebral palsy who seldom require care by pediatric specialists (Jalkut, & Allen, 2009; Peter, Forke, Ginsburg, & Schwarz, 2009; Stewart, 2009; Mutze, et al., 2011; Zack, et al., 2003).

Though the trained congenital cardiothoracic surgeon may be best suited to continue to care for this growing patient population, other health care professionals educated in the care of this specific population are in short supply. Despite the growing number of adult patients with congenital heart disease, there are few of these patients within any one setting to provide learning experiences for medical students and for the development of physician expertise to meet the unique needs of this patient group. Very few programs exist for cardiologists, sonographers, or

nurses in this specialized field to gain both substantive knowledge and experience in caring for ACHD patients (Dearani, et al., 2007).

Pediatric health care professionals are uncomfortable caring for adult patients with unfamiliar adult health problems compounding their original congenital heart disease diagnosis. Some of the issues cited by Dearani, et al. (2007) are selection of medications, different dosing recommendations and regimes, and the management of adult co-morbidities such as diabetes mellitus. While an adult medical treatment team may be consulted to help co-manage this population appropriately, nursing does not have the same equivalent resources available. Nurses trained to take care of pediatric patients do not have an available nurse who has been trained to take care of adult patients to co-manage the patient care. Pediatric caregivers are uncomfortable with a range of adult healthcare concerns, from the safest form of birth control, to nicotine replacement therapy and alcohol withdrawal, conditions seldom encountered in the PICU or CTICU (McDonnell, Kocolas, Roosevelt, & Yetman, 2010).

Among the challenges of caring for the adult patient with CHD within a pediatric setting are the practical issue of administering prescribed medications. In pediatric settings, many medication dosages are weight-based calculations, while in adult settings there are standard adult dosages for many medications that would be weight based for a pediatric patient. Nurses are responsible for verifying that correct drug dosages are ordered and administered. The difference is particularly relevant when administering emergency medications (Thompson, 2007).

Significance

Congruence of DNP Role with Developing Guidelines for Quality Patient Care

The recently published guidelines by the International Society of Heart Lung Transplantation (ISHLT) for the medical care of patients who have received heart, lung, or heart-

lung transplantation are specific but limited. Many heart lung transplant patients are adult patients that have congenital conditions that have been treated with a transplant. This adult patient population can be cared for post-transplant in pediatric institutions. The ISHLT guidelines include only issues regarding peri-operative and immediate post-operative concerns (Costanzo, et al., 2010). This does not address floor nursing care for either adult patients within the pediatric setting or pediatric patients within the adult care setting

The components for physician care that make up the competencies required to care and manage patients with heart failure, both adult and pediatric, are outlined specifically in the ACCF/AHA/ACP/HFSA/ISHLT 2010 Clinical Competence Statement on Management of Patients With Advanced Heart Failure and Cardiac Transplant: A Report of the ACCF/AHA/ACP Task Force on Clinical Competence and Training (Francis, et al., 2011). The task force did not outline the competencies for any healthcare professional field other than medicine, though multiple studies have highlighted the need for specifically trained nursing and allied health care providers, along with qualified specialists in multiple areas surrounding cardiology (Dearani, et al., 2007). Specialty trained physicians and specialty areas within hospitals have become more universal. Over time a type of specialty area, pediatric cardiac intensive care units and/or pediatric cardiothoracic intensive care units, have evolved in tertiary referral centers and care for adult patients as well as pediatric patients with CHD (Thompson, 2007).

Project Purpose

The purpose of this narrative project is to describe the knowledge, skills, attitudes, and resources RNs perceive as necessary to care for adults with CHD at Nationwide Children's Hospital Heart Center.

Chapter Two: Review of Literature

Framework

The Quality and Safety Education for Nurses (QSEN) project addresses the preparation of nurses with the knowledge, skills, and attitudes (KSA) necessary to improve the quality and safety of patient care (Ironside, 2007). KSA uses the broad theory of learning from Bloom (1956) that looks at the cognitive, affective and psychomotor aspects of learning. The theory provides the framework to examine the knowledge, skills, and attitudes necessary for caring for adult patients with CHD on a pediatric ward.

PICO Question

The PICOT question that guided this project was: What are the knowledge, skills, attitudes, and resources pediatric registered nurses identify as necessary to provide care to adult patient with CHD in a pediatric hospital?

Project Questions

1. What are the care experiences of pediatric bedside RNs caring for ACHD patients that highlight deficits in knowledge, skills, attitude, or resources for adult care in a pediatric hospital?
2. What are the knowledge, skills, attitudes, and resources described by pediatric registered nurses as essential to caring for adult patients with CHD during hospitalization within a pediatric facility?

Literature review

The research related to adult patients being cared for in a pediatric environment, or even vice versa a child being taken care of in an adult setting are few in number and are mainly descriptive in nature. A systematic inclusive review of the published literature was done with the

use of PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochran, Worldcat, Agency for Healthcare Research and Quality's database (AHRQ), and Google Scholar both independently and with the help of two research librarian services at the Ohio State University Health Sciences library and the NCH Heart Center .The search terms used were (adult OR adults OR adult congenital heart) AND (pediatric nurse OR pediatric nursing OR pediatric) AND (knowledge OR competency OR skills OR resources OR attitudes). A total of thirteen journal articles were found with publication dates ranging from 1998 to 2011.

Early journal articles, from the late 1990's to the early 2000's, focus on adult areas taking care of pediatric patients (Breslawski, 2004; Kimberly, 2002; Hazinski, 1998). Studies within this time frame called for staff training so that appropriate developmental care could be given.

More recent articles focused on education programs for either adult nurses taking care of pediatric patients or the increased admissions of adults in pediatric areas. Education focused on pediatric developmental needs and pediatric pathophysiology that was implemented showed increased confidence from the nursing staff (Offord, 2010; Macyk, 2011). Articles specifically highlighting adult congenital patients in the pediatric setting called for better preparation for hospitalization as well as identifying resources and basic training regarding adult needs (McDonnell, et al, 2010; Tan, et al., 2009) along with the need to identify strategies to care for adult congenital patients who have "unique needs" (Goodman, et al., 2011). Though articles noted that adults being cared for in pediatric settings were receiving acceptable care per their mortality rates (Mott et al, 2002; Dearani, 2007) and that the adults themselves had few concerns about being cared for in a pediatric setting (Tomlin 2011) there was no literature noting how to educate; we are beyond 'training' nurses or what training should be included (Goodman, et al., 2011; McDonnell, et al., 2010).

Chapter Three: Design

Project Design

The study used focus group interviews. Focus groups are well suited to this project because of the exploratory nature of the project in that the knowledge obtained by the RNs through their experience is complex and not adequately described by the limitations of a survey with specified answers. Exploration is the best option for describing this phenomenon since there was no body of evidence found regarding nursing knowledge, skills, attitudes, and resources connected to this patient population. Focus group interviewing is an exploratory technique that facilitates a greater understanding of the topic by capturing themes and details not readily acquired through observation or fixed survey (Krueger, 1994). The dynamic of the focus group creates synergism among the participants by stimulating recall of additional dimensions of the experience under discussion (Morgan, 1988; Stewart, Shamdasani, & Rook, 2007). In addition the focus group technique supports achieving depth of understanding rather than breadth.

The emergent design follows inductive reasoning through the iterations of the data collection and analysis. The design, project questions, and methods can evolve even as data collection and analysis occur because the meaning attributed by the individual to their experience is highly dependent on the context of the experience. The data about this phenomenon cannot come from only one person's perspective and must address the multiple perspectives of many individuals (Lincoln & Guba, 1985).

IRB Approval

The Nationwide Children's Hospital IRB granted institutional review board approval on January 17, 2013. An expedited review was requested because this study does not involve a vulnerable population or personal health information and poses no more than minimal risk to

participants. Risks to participants are related to self-disclosure in a group of peers. The possibility exists that individual experiences or opinions could be shared outside the focus group despite the moderator's admonition to maintain privacy. Participants are nurses working on a pediatric cardiology floor with one or more year's experience upon said floor.

Sample

Accessible Population

This study focused on the insights of RNs working within the cardiology floor/step-down at The Heart Center at Nationwide Children's Hospital in Columbus, Ohio. Thirty-seven nurses work within the cardiology floor/step-down. Ages range from 22 years old to 40 years old with nursing experience on the cardiology floor ranging from less than one year to over a decade. They are predominantly female and work full-time. Those RNs, having worked greater than one year, brought substantial content expertise to the discussion based upon their experiences participating in the care of the ACHD population. The ACHD patient assignment has grown from a rare patient assignment to a routine encounter (Crumb, 2011) over the last few years at Nationwide Children's Hospital.

Inclusion and Exclusion Criteria

The nurses who were eligible to participate have been permanent registered nursing staff at NCH with a minimum of 1 year experience working on H4A, a cardiology floor at NCH. One year of experience was chosen to assure that the participant has a basis on which to compare and contrast pediatric and adult congenital heart care from the perspective of an RN oriented to care for children now caring for adult patients in a pediatric hospital. RNs with less than 1 years of experience or occupying a position of reporting authority (managers or directors) over other RNs

in the Heart Center (due to potential conflict of interest with professional roles within the health care team) were not eligible for participation.

Setting

Nationwide Children's Hospital is a freestanding facility in Columbus, Ohio. It currently has over 300 beds. The Columbus Ohio Adult Congenital Heart Program at Nationwide Children's Hospital is one of the largest ACHD programs in the United States and admits nearly all of its patients needing surgery or cardiac catheterization procedures to Nationwide Children's Hospital. A recent review of care of ACHD at Nationwide Children's Hospital (Crumb, et al., 2011) identified 782 patients undergoing 1,490 procedures or non-elective admissions from 2002 through 2007. The number of patients per year during the study period showed steady growth. Thus the RNs at Nationwide Children's Hospital Heart Center have experienced a significant growth in the number of adults with congenital heart disease under their care.

Methods

This project used an exploratory approach because the issue-- requisite knowledge, skills, attitudes, and resources for RNs caring for ACHD-- have not been previously defined or described from the perspective of the nurses. The information about requisite knowledge, skills, attitudes, and resources may be found in the stories of the RNs who provide care to ACHD without benefit of a formal training program. The content of the focus group interview was subjected to narrative content analysis. The technique of focus group interviews and content analysis are especially useful when exploring the needs and perspectives of health care teams (Coté-Arsenault & Morrison-Beedy, 1999; Morrison & Peoples, 1999; Sharts-Hopko, 2001). The focus group technique was a natural fit for this project because the participants-- RNs involved in ACHD care-- are already professional colleagues within a larger health care team

providing care for ACHD patients. They are experienced caregivers with in-depth experience or content expertise in what is the central topic explored in the focus group interviews.

Recruitment

Eligible RNs were invited to participate through an email invitation (Appendix A) and verbally on the day of the interviews. The invitations included the purpose of the study, the format of the study, the dates and duration of the focus groups, risks and benefits of participation, and contact information. A scripted telephone call from Tracy Heard followed the invitations within 1 week of the email to provide an opportunity to answer questions if interest had been shown from the emailed invitations. A reminder telephone call from Tracy Heard would have taken place the day before the focus group (Appendix C). Individuals that participated only responded to the in-person invitation process.

Procedures

To facilitate maximal participation, three to five focus groups consisting of 3-5 participants each were conducted in a private area on the cardiology floor, a conference room (Stewart, 2007). Light refreshments were provided to participants. The focus group interviews were scheduled for a 1 hour time period with established questions to guide the exploration and discussion (Appendix D). A moderator and co-moderator facilitated the focus groups. The moderator asked the questions to the focus group. The moderator for three of the four groups had experience in leading a focus group. In addition to the moderator, there was a co-moderator present to record the process of the interview, noting such things as tone of voice, body language, or level of animation (e.g., thoughtful pauses versus rapid-fire responses) of the participants and to present a summary of key points of the discussion at the end of each focus

group. Participants were provided written informed consent prior to the beginning of the interview (Appendix E).

Each focus group was audio-recorded and transcribed. The focus group recordings were stored in a locked safe after verifying the transcriptions. As data was aggregated from focus groups, subsequent groups were asked to validate recurrent themes brought up by previous focus groups.

1. Introduction of both moderator and co-moderator.
2. Consent form collection of signed forms prior to group interview
3. Set the stage. Explain the background to the study and the purpose of the study.
4. Moderator will read the script and facilitate responses.
5. Co-moderator then concluded focus group.
6. Moderator and Co-moderator review interview.

Data Analysis

The focus group data was analyzed using the classic analysis strategy described in Krueger and Casey.' (2009). Preliminary analysis of data from each focus group occurred before the next focus group was conducted. The process of data analysis began with the co-moderator's verbal summary of the major points of the discussion at the end of the focus group. The participants were asked to comment on whether or not the summary accurately and completely reflected the key points of the discussion. They were asked if they would like to add anything further.

After the conclusion of the focus group, the moderator and co-moderator debriefed each other. This recorded conversation might include topics such as the dominant themes or ideas shared, unexpected findings, or usefulness of the questions (Krueger, 1994). Following

transcription of the data the moderator reviewed the data and compared it with the original recording for accuracy.

The scissor-and-sort technique was used to analyze the findings (Stewart, Shamdasani, & Rook, 2007). To promote integrity of the data analysis, a faculty member (GSB) whose areas of expertise is medical-surgical nursing with experience in the management of the adult congenital heart patient also read the transcripts and verified or amended classifications. Coding is the association of labels to common ideas or concepts that appear in the narrative. Codes can be in-vivo (emerging from the words of participants) or in-vitro (pre-determined by the investigator) (Creswell, 2007). Coding was applied to the data at multiple levels, called units of analysis (Krippendorff, 1980). Coding was at the level of words, phrases, and sentences. Later rounds of coding considered the level of participant comments, which may be as much as a paragraph. This moves the analysis from open coding to substantive coding to ultimately theoretic coding.

Each interview was broken down into five questions and a summary section. All of the responses to one question were reviewed together. Factors that affected the weight or importance of the comments or themes will be the frequency, specificity, emotion, and extensiveness of the topic (Krueger & Casey, 2009). Frequency is not as important for analysis as extensiveness. Frequency is the number of times one thing is said while extensiveness is how many times one thing is said by multiple people at different times.

Enhancing rigor. With the narrative exploration used with this project, rigor establishes the trustworthiness in the results of the focus groups (Lincoln & Guba, 1985) The components of qualitative rigor which can be applied to this narrative exploration are: credibility, dependability, and conformability. The techniques used in this inquiry to enhance credibility included prolonged engagement in the setting by the focus group leader, data review

triangulation, and member checks. The focus group leader has been in practice at the site of inquiry for more than 6 years, which is sufficient time to gain appreciation and understanding of the setting. The second data reviewer was a doctoral committee member with expertise in medical surgical nursing and the management of the adult congenital heart patient. Member checking is the process of verifying the accuracy of the primary investigator's interpretation with the participants. This verification occurred at the conclusion of the focus group interviews and by inviting participants' comments to written summaries after data were analyzed. However, no comments were received.

Chapter Four: Findings

Results

The interviews consisted of essentially five questions and a final summary. Each of the interview questions responses was compared together. Each interview included 3 to 5 responders. Everyone had a chance to respond to each question and make additions or clarifications at the summary.

The image of the adult congenital heart disease patient was described as blue, clubbed, with ascites or someone who has social developmental delays, and as someone who isn't compliant; they've returned to the hospital "because they haven't taken something," (focus group interview #1). The experience of taking care of the adult patient was seen as generally positive. The terms noncompliance, ascites, and how it was a positive experience to take care of the adult patient was heard from more than one interview and from more than one participant at each interview. One item that was noted to have improved the experience of taking care of the adult patient was that the plan was consistent for the patient since the adult team rounded with the cardiology floor team.

The second question asked what the comparisons and contrasts were between the adult and pediatric congenital heart population. Poor perfusion, "blue" "color looks bad" (focus group interview #1 and #2) in the adult patients in comparison to the pediatric patients. The amount of frustration the nurse may have was brought up with this question along with the idea of the experience being "more down" (focus group interview #2) when working with the adult patient then the pediatric patient. Pain medications were brought up during two different interviews: the use, misuse, and how much it's needed. The act of "catering to the patient" (focus group interview #4) and the difficulty of getting the adult patient up and moving after surgery was

noted along with the statement that a patient had said they were embarrassed to be at a Childrens' hospital (focus group interview #4). Additional comments followed about the inability for the adult patients to become independent. The adults were seen as dependent on their parents.

The third question asked that the participants think back to their first nursing experience with an adult patient. Compliance, frustration, neediness or demanding interactions, poor coloring, end-of-life and quality-of-life were brought up multiple times during more than one interview from more than one participant. The concept of the nurse needing to be confident and assertive which may come from experience was brought up multiple times by more than one nurse during one session.

The fourth question looked at the challenges that surround this patient population. The need for different equipment, frustration from the patient, and the rules being made for pediatric patients needing to be followed by the adult patients were brought up by different individuals during different sessions. Particularly, rules surrounding independent travel or allowing visitors that were not their parents or who wanted to visit beyond the set visitation hours were of concern.

The fifth question asked what specific skills, knowledge, resources, and/or attitudes were essential to have when caring for an adult patient. The need for social work involvement was noted. Direct physician involvement was stated to be important. Having good communication, rapport, along with being assertive and direct was stated multiple times by different nurses. The difference in assessments between adult and pediatric patients was mentioned in two interviews. No specific skills besides the placement peripheral intravenous catheters were mentioned.

In the summaries, within and at the ends of the focus group interviews, the terms noncompliant, the physical state of a failed Fontan (surgery name), and overall positive experience repeated themselves. One group hoped to hear from the patients what they would like to improve in their stay. One nurse put it as they are “their family” as they “really depend on you” and that the nurses want to do the best that they can for them.

Chapter Five: Discussion, Conclusions and Implications to Practice

Discussion

The common themes that came from the four interviews were noncompliance from the patients in regards to their healthcare, particularly taking their medications correctly frustration from the nurses toward the patients but also from the patients towards not getting what they want, mainly independent travel within the hospital and unlimited visitors. Developmental aspects of caring for chronically ill adults and the overall difference in assessment skills were mentioned in regards to the adult chronic conditions involving heart failure. How the nurse needs to care for the patient, with good communication skills, assertive and direct language, was brought up repeatedly. How to learn these skills or share these skills through orientation was not expressed. The only way to become proficient in these skills that the nurses referred to was experience.

Frustration, compliance, and the topic of pain medications all come together within one scenario. The pediatric nurse, when taking care of an adult patient, is placed into an unfamiliar role,. They have little control over what or how the adult patient behaves in the hospital. They can directly communicate with the adult patient, but may not have a strong relationship. Without a good basis of trust, a feeling that the patient is noncompliant at home leading them to this admission and possibly prior admissions, the nurse becomes leery of using pain medications.

Learning how to communicate to adult patients, to be appropriate to their developmental needs of independence, can be a part of orientation or continuing education. A bedside RN remembered one lecture regarding adult congenital heart patients. She referred to the lecture after being asked how she developed skills to work with adult patients in her pediatric unit. Prompting about orientation and how they would orient a new nurse didn't bring up any ways to share these

skills besides reminding the new nurse to let the adult be independent and that creating a rapport is important along with being assertive, direct, and flexible with your timing of nursing cares.

Though the differences in assessments of adults and pediatric patients were brought up, nurses were vague. It was said that the adults were easier and that they could be harder. The concern the nurses showed by repeatedly bringing up the chronic and end-of-life nature of the patient's condition highlights the importance of the assessments skills on this cardiology floor. The lack of concern regarding specific adult items; correct dosing of medications, well fitting equipment, and specific chronic medical conditions such as diabetes may indicate a high comfort level regarding the items or a lack of knowledge. Without further inquiry into these areas the underlying reason for not being concerned about some high risk issues is unknown.

Conclusions

The nursing staff caring for the adult patients on the pediatric cardiology floor at Nationwide Children's Hospital want to give the best possible experience to their patients regardless of their age. The ability to articulate how to accomplish that care is lacking. Current orientation methods do not regularly include information on adult development, interpersonal communication techniques, or specific pathophysiology findings within the chronically ill heart failure patient.

Rules and regulations within Nationwide Childrens Hospital regarding visitation may need to be reassessed in regards to the adult patient population. The use of resources, discounts for parking, social workers and the adult congenital heart team consulting service, for the patients was appropriate. Equal use of those same resources, psychology, social work, and the adult congenital heart team, for the nursing staff may help with the frustration and lack of general knowledge regarding the pathophysiology of terminal heart failure.

Future questions require patient input. Do they have the same or different perceptions then the nurses in regards to the questions that were asked? Do the patients feel that they are frustrated or do the patients perceive the nurses to be frustrated? Do the patients perceive that they are noncompliant? Would they feel that their hospital stay was better if they had more independence? Nurses taking care of adult patients in the pediatric setting beyond the floor need to be included in the conversation, also. Do intensive care nurses have the same or different concerns then the floor nurses? Do the emergency department nurses have the same or different challenges with this patient population? Are all of the pediatric nurses within the hospital aware of the resources they have to work with their adult patients?

Limitations

The participants in this project came from a single pediatric hospital with an established adult congenital heart disease program. Because of this single specific setting the participants may not have perceived the same knowledge and skills needed as RNs in a different setting. These focus groups may not have captured the full spectrum of knowledge, skills, attitudes, and resources needed by RNs to care for ACHD.

Selection was not random, however all nurses from the floor were equally exposed to the focus group invitations. The interviews were done on different days of the week along with one interview being done on night shift and on a weekend shift to include participation from different subgroups of fulltime nurses. The experience of the first group may have affected subsequent participants. Future studies will need to explore the generalization of these findings.

Summary

ACHD patients are currently being cared for within pediatric facilities. The nursing staff caring for the adult patients among their pediatric patients feels frustrated about both the patients themselves and the care process.

The literature review shows that training is needed for all levels of healthcare workers from the call for fellowships in medicine to the lack of any designated training for nursing staff. Our current nursing staff stated that they are working with experience as their main guide.

More information is needed to make broad statements on how to improve the care for this underserved patient population. Future projects looking at interdisciplinary care and the patients' perceptions are needed to get a well-rounded view of the care for these patients within a pediatric setting.

Implications

Essential IV: Information Systems/Technology and Patient Care Technology for the Improvement and Transformation of Health Care

Graduates of doctorate of nursing practice (DNP) programs have the skills and knowledge to support and improve both patient care and systems of care within large healthcare systems. They assume leadership in managing patient care, assessing the safety and efficiency of both patient care and system processes, and ultimately determining the best care for patients in their specialized area of practice (American Association of Colleges of Nursing, 2006). Thus the doctoral-prepared and acute care pediatric nurse practitioner is an ideal professional to identify characteristics and lead quality improvement efforts to address this gap in care for the adult patient with CHD (Dearani, et al., 2007).

An area for education related to nursing practice both at the bedside and at the system level within healthcare systems that find themselves caring for adult patients in a

pediatric setting is open for a Doctoral prepared nurse. To be able to bring together the clinical aspects of evidence-based practice and see the global picture of this underserved patient population uniquely sets the DNP as a potentially well-trained leader in this field.

References

- Adult Congenital Heart Association. (2010). *ACHA's VISION 2020 Forum: From planning to implementation*. Retrieved from <http://www.achaheart.org/Portals/0/pdf/V2020/V2020forumreportfinal.pdf>
- American Association of Colleges of Nursing. (2006). *The essentials of doctoral education for advanced nursing practice*. Washington, D.C.: Author. Retrieved from <http://www.aacn.nche.edu/publications/position/DNPEssentials.pdf>
- Berghammer, M., Dellborg, M., and Ekman, I. (2006). Young adults experiences of living with congenital heart disease. *International Journal of Cardiology*, 110, 340-347.
- Breslawski, J. L. (2004). Caring for the adolescent trauma patient in the adult critical care setting. *Journal of Trauma Nursing*, 11(3), 111-116.
- Child, D. G., Collins-Nakai, R. L., Alpert, J. S., Deanfield, J. E., Harris, L., McLaughlin, P. & Williams, R. G. (2001). Task force 3: Workforce description and educational requirements for the care of adults with congenital heart disease. *Journal of the American College of Cardiology*, 37(5), 1183-1187.
- Costanzo, M. R., Dipchand, A., Starling, R., Anderson, A., Chan, M., & Desai, S. et al. (2010). Guidelines for heart transplant care. *The Journal of Heart and Lung Transplantation*, 29, 8, 914-955.
- Coté-Arsenault, D., & Morrison-Beedy, D. (1999). Practical advice for planning and conducting focus groups. *Nursing Research*, 48(5), 280-283.
- Creswell, J. W. (2007). *Qualitative inquiry & research design*. Thousand Oaks, CA: Sage.
- Crumb, S. R., Cook, S. C., Cheatham, J. P., Galantowicz, M., Feltes, T. F., Phillips, A., & Daniels, C. J. (2011). Quality outcomes of ACHD patients undergoing cardiovascular

- procedures and hospital admissions in a free-standing children's hospital. *International Journal of Cardiology*, 146, 326-329.
- Dearani, J., Connolly, H., Martinez, R., Fontanet, H., and Webb, G. (2007). Caring for adults with congenital heart disease: successes and challenges for 2007 and beyond. *Cardiology in the Young*, 12:2, 87-96.
- Dougherty, C., Dewhurst, T., Nichol, P., and Spertus, J. (1998). Comparison of three quality of life instruments in stable angina pectoris: Seattle Angina Questionnaire, Short Form Health Survey (SF-36), and Quality of Life Index-Cardiac Version III. *Journal of Clinical Epidemiology*, 51, 569-575.
- Foster, E., Graham, T. P., Jr., Driscoll, D. J., Reid, G. J., Reiss, J. G., Russell, I. A., et al. (2001). Task force 2: Special health care needs of adults with congenital heart disease. *Journal of the American College of Cardiology*, 37:5, 1176-83.
- Francis, G. S., Greenberg, B. H., Hsu, D. T., Jaski, B. E., Jessup, M., LeWinter, M. M., (2011). ACCF/AHA/ACP/HFSA/ISHLT 2010 Clinical competence statement on management of patients with advanced heart failure and cardiac transplant: A report of the ACCF/AHA/ACP task force on clinical competence and training. *Journal of the American College of Cardiology*, 56:5, 424-453.
- Goodman, D., Hall, M., Levin, A., Watson, S., Williams, R., Shah, S., and Slonim, A. D. (2011). Adults with chronic conditions originating in childhood: Inpatient experience in Children's Hospitals. *Pediatrics*, 128(1), 5-13.
- Hazinski, M. F. (1998). Children in the adult ICU: Preparation and practice. *Critical Care Nurse*, 18(6), 82-87.
- Ironside, P.M. (2007). Exploring the Complexity of Advocacy: Balancing Patient-Centered Care

and Safety. (n.d.). Retrieved May 21, 2007, from

<http://www.qsen.org/teachingstrategy.php?id=58>

Jalkut, M. and Allen, P. (2009). Transition from pediatric to adult health care for adolescents with congenital heart disease: A review of the literature and clinical implications. *Pediatric Nursing*, 35:6, 381-387.

Kimberly, A. (2002). Caring for adolescents in the adult intensive care unit. *Critical Care Nurse*, 22(2), 80-99.

Kools, S., Tong, E. M., Hughes, R., Jayne, R., Scheibly, K., Laughlin, J. and Gilliss, C. (2002). Hospital experiences of young adults with congenital heart disease: Divergence in expectations and dissonance in care. *American Journal of Critical Care*, 11(2), 115-125.

Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Beverly Hills: Sage.

Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Newbury Park, CA: Sage.

Krueger, R. A. and Casey, M. A. (2009). *Focus groups: A practical guide for applied research* (4th ed.). Los Angeles, CA: Sage

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Macyk, I. (2011). A creative strategy to enhance pediatric competency among adult care nurses. *The Journal of Continuing Education in Nursing*, 42(1), 14-15.

Marelli A., Mackie, A., Lonescu-Ittu, R., Rahme, E., and Pilote, L. (2007). Congenital heart disease in the general population: Changing prevalence and age distribution. *Circulation*, 115:2, 163-172.

- Marino, B., Uzark, K., Ittenbach, R., and Drotar, D. (2010). Evaluation of quality of life in children with heart disease. *Progress in Pediatric Cardiology*, 29, 131-138.
- McDonnell, W. M., Kocolas, I., Roosevelt, G., and Yetman, A. (2010). Pediatric emergency department use by adults with chronic pediatric disorders. *Pediatric Adolescent Medicine*, 164, 572-576.
- Moons, P., Van Deyk, K., Budts, W., and De Geest, S. (2004). Caliber of quality-of-life assessments in congenital heart disease: A plea for more conceptual and methodological rigor. *Archives of Pediatrics and Adolescent Medicine*, 158, 1062-1069.
- Morgan, G., & Ramirez, R. (1984). Action Learning: A holographic metaphor for guiding social change. *Human Relations*, 37, 1-28.
- Morrison, R. S., & Peoples, L. (1999). Using focus group methodology in nursing. *Journal of Continuing Education in Nursing*, 30(2), 62-65.
- Mott, A. R., Fraser, C. D., McKenzie, E. D., Bezold, L. I., Andropoulos, D. B., Reul, G. J., Miranda, C. H., Bedford, S. L. and Feltes, T. F. (2002). Perioperative care of the adult with congenital heart disease in a free-standing tertiary pediatric facility. *Pediatric Cardiology*, 23, 624-630. Doi:10.1007/s00246-002-0236-y
- Mutze, U., Roth, A., Weigel, J. F. W., Beblo, S., Baerwald, C. G., Buhrdel, P. et al. (2011). Transition of young adults with phenylketonuria from pediatric to adult care. *Journal of inherited metabolic disorders*, 34, 701-709.
- Offord, R. J. (2010). Caring for critically ill children within an adult environment – An educational strategy. *Nursing in Critical Care*, 15(6), 300-307.
- Peter, N. G., Forke, C. M., Ginsburg, K. R. & Schwarz, D. F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*, 123, 417-423. Doi:10.152/peds.2008-0740

- Roshan, E. R., & Ali, T. S. (January 01, 2011). Knowledge and Practice Gaps among Pediatric Nurses at a Tertiary Care Hospital Karachi Pakistan. *Isrn Pediatrics*, 2011.
- Sharts-Hopko, N. C. (2001). Focus group methodology: When and why? *Journal of the Association of Nurses in AIDS Care*, 12(4), 89-91.
- Simko, L. and McGinnis, K. (2005). What is the perceived quality of life of adults with congenital heart disease and does it differ by anomaly? *The Journal of Cardiovascular Nursing*, 20:3, 206-214.
- Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental medicine and child neurology*, 51:4, 169-173. Doi:10.1111/j.1469-8749.2009.03419.x
- Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2007). *Focus groups: Theory and practice* (2nd ed.). Thousand Oaks, CA: Sage.
- Stommel, M. & Wills, C. (2004). *Clinical research: Concepts and principles for advanced practice nurses* (2nd ed.). Philadelphia, PA: Lippincott Williams & Wilkins
- Tan, J., Cox, R., Shannon, P. and Payne, D. (2009). Adolescent and young adult health in a children's hospital: Everybody's business. *Journal of Paediatrics and Child Health*, 45,715-719. Doi:10.1111/j.1440-1754.2009.01600.x
- Thompson, L. (2007). Care of the patient with adult congenital heart disease. *Critical Care Nursing Quarterly*, 30:1, 3-11.
- Tomlin, M. A. & Gosney, K. (2011). Adult congenital heart care in a pediatric setting- A patient's perspective. *Journal of Cardiovascular Nursing*, 26(4), 329-335.

Warnes, C., Williams, R., Bashore, T., Shild, J., Connolly, H., and Dearani, J. et al. (2008).

ACC/AHA 2008 Guidelines for the management of adults with congenital heart disease:

Executive summary. *Circulation*, 118, 2395-2451.

Wauthy, P., Massaut, J., Sanoussi, A., Demanet, H., Morissens, M., and Damry, N. et al. (2011).

Ten-year experience with surgical treatment of adults with congenital cardiac disease.

Cardiology in the young, 21, 39-45.

Werrett, J. A., Helm, R. H., & Carnwell, R. (January 01, 2001). The primary and secondary care interface: the educational needs of nursing staff for the provision of seamless care.

Journal of Advanced Nursing, 34, 5, 629-638.

Zack, J., Jacobs, C. P., Keenan, P. M., Harney, K., Woods, E., Colin, A. A., et al. (2003).

Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatric pulmonology*, 36, 376-383. Doi:10.1002/ppul.10342

Appendix A

Invitation to participate in a study

Your experience is valuable!



If you participate in this study, you will:

- Join 2-4 other RNs who care for adults with congenital heart disease in a focus group interview that will last about 1 hour
- Participate in the focus group discussion by sharing your experiences and what you have learned about caring for adults with congenital heart disease

Participate in a research study.

Share what you have learned as an RN caring for adults with congenital heart disease.

We will keep all data collected confidential

Location of study: Nationwide Children's Hospital

To take part in this research study or for more information, please contact 614-722-9469

Appendix B

Telephone Script

Hello, my name is (Tracy Heard). I am an Advance Practice Nurse at Nationwide Children's Hospital. I am assisting Dr. Gerene Bauldoff and Regina Prusinski in research to learn more about what nurses in the Heart Center at Nationwide Children's Hospital believe is important knowledge and skills for caring for adult patients with congenital heart disease. Did you receive the informational email inviting you to participate?

(if yes, proceed; if no, ask if they would be interested in learning about the study.

If interested, continue; if not thank them for their time and end the call).

If you participate in this study, you will:

- Join 2-4 other RNs who care for adults with congenital heart disease in a focus group interview that will last about 1 hour
- Participate in the focus group discussion by sharing your experiences and what you have learned about caring for adults with congenital heart disease

Your participation in this study is voluntary. This means that you do not have to participate in this study unless you want to. Would you be willing to answer some questions to help determine if you are eligible for this study?

Good. I will read a list of questions.

1. Are you a nurse in the Heart Center at Nationwide Children's Hospital? Y N
2. Have you been in this role for at least 1 year? Y N
3. Do you hold a supervisory role over other RNs in the Heart Center? Y N

(Subject is eligible if the answers are 1. Yes, 2. Yes, and 3. No. If subject is not eligible, thank them for their time, say they are not eligible and end the call. If they are eligible, proceed).

The purpose of this research study is to learn more about the experiences of bedside nurses in a pediatric hospital who care for adult patients with congenital heart disease. Another purpose is to find out what these RNs think is important knowledge, skills, and resources for an RN to have in order to care for adults with congenital heart disease. We estimate that about 15 RNs will participate in this study. You will be asked to join 3-5 other RNs in a focus group interview. The focus group will take about 1 hour of your time. During the focus group you will be asked to talk about your personal experiences of caring for adults with congenital heart disease. The discussion will be tape recorded to avoid missing anyone's comments. There is a small chance that some of the questions may make you feel uncomfortable. You don't have to answer those questions if you don't want to. In fact you don't have to answer any question that you choose not to answer. And that is fine.

All the information you provide, including your name, will be strictly confidential. In fact all names will be deleted and replaced with artificially created IDs in the transcription of the tape. No names will be attached to any comments in reports of the study. Your comments will remain confidential. There will be no way to identify individual participants.

The only risk to you might be some discomfort discussing your experiences in front of your colleagues or if your comments were ever shared by another focus group member. There are no other expected risks to you for helping with this study. There are also no expected benefits for you either.

Do you have any questions?

Are you interested in participating in this study?

Can we set up a focus group time?

Thank you for your interest in this project.

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact the IRB office at 1-800-678-6251 or (614) 722-2708.

Appendix C

Reminder Script

Hello, my name is (Melissa Leek or Tracy Heard) at Nationwide Children's Hospital. I am calling to remind you of the focus group you are scheduled to attend tomorrow at (TIME) in (ROOM) at Nationwide Children's Hospital. Thank you for participating. We look forward to seeing you.

Appendix D

Interview Guide

Thank you for agreeing to participate in this focus group discussion about caring for adult patients with congenital heart disease in a pediatric hospital. You were each invited to participate in this study because you are advanced practice nurses who work at Nationwide Children's Hospital and take care of adult patients with congenital heart disease. We want to hear your experiences, thoughts, and feelings about caring for adult congenital heart patients here.

Today we will be discussing your experiences in caring for adult patients in a pediatric hospital. We want to know what is good, not so good, and what you think is important to your ability to care for adult congenital heart patients.

Before I ask you to read and sign the consent form, let me highlight a few points in the consent. This discussion is part of a research project to understand the requisite knowledge and skills for caring for adults with congenital heart disease. Your participation is voluntary. You may choose to stop participating at any time. If you decide to stop participating there will be no penalty. There is no direct benefit for you to participate in this study. The only risks are those of personal disclosure. It is possible you may feel some discomfort discussing your experiences or feelings about certain experiences. Are there any questions? (Answer questions) Please read and sign the consent form. (Co-moderator name) will collect your signed form.

Before we begin, let me suggest a few things that will make our discussion more productive. Please speak up, but only one person at a time. If you have a cell phone, please either turn it off or set it to vibrate. We are tape recording the discussion so we don't miss any of your comments. During the discussion we will be on a first name basis but all names will be deleted and replaced with artificially created IDs in the transcription of the tape. No names will be attached to any comments in reports of the study. Your comments will remain confidential. Even though we will keep this information confidential, we all need to respect each other's privacy and keep what is said here in the discussion confidential: You should not say anything here that you would not want to be repeated, even inadvertently, outside this room.

Each of you has received a copy of the questions for this discussion. I will be moving the discussion from one question to the next. It is important that we hear from each of you because you each have a different experience. In order to hear from everyone and to keep us on track for time I may limit some discussion or I may encourage people who haven't spoken up to do so.

Opening	Introduce the Moderator and Co-moderator, obtain consent if not already obtained, and hand out the interview questions in written format.
Introduction	When you hear the words "adult congenital heart disease patient," what comes to mind? Summarize responses and ask if there are any additional thoughts.
Transition	How do you compare the ACHD population and the pediatric congenital heart population to one another?

	Summarize responses and ask if there are any additional thoughts.
Transition	Think back to one of the first times you took care of an adult congenital heart patient here: What was that experience like? Summarize responses and ask if there are any additional thoughts.
Key	What are the challenges or difficulties in taking care of ACHD patients in a pediatric facility? (Can you give an example?) Summarize responses and ask if there are any additional thoughts.
Probe	What knowledge or attitude do you think is essential to care for ACHD patients? How did you acquire that knowledge? Summarize responses and ask if there are any additional thoughts.
Probe	What skills or resources do you think are essential to care for ACHD patients? How did you gain those skills? Summarize responses and ask if there are any additional thoughts.
Ending	I'm going to wrap up our discussion with some ending questions. First, I'd like each of you to share in one sentence what was the key thing that you heard tonight about RNs caring for ACHD. What is the main piece of advice would you give to someone developing an orientation or education program for RNs to specialize in adult congenital heart disease? My last question before (CO-MODERATOR NAME) gives us a summary of the discussion, is—is there anything we didn't discuss that we should have or anything I didn't ask that I should have—to help us get a good understanding of the requisite knowledge and skills for caring for ACHD patients.
Co-moderator summary	(NAME) is going to give us a summary of the discussion. As she is reading the summary, please note if there are any things you would like to clarify or any additional information you want to add to anything we discussed here this evening.
Final	Is there anything else you would like to add?
Closing	Thank you for your time and participation in this discussion. You will be receiving a follow-up telephone call from our administrative assistant asking if anything occurred after you left here tonight that you would like to share.

Appendix E

Consent Form for focus group participation

CONSENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

STUDY TITLE: Pediatric Registered Nurses' Perceptions of the Knowledge, Skills, Attitudes, and Resources Required to Care for Adult Congenital Heart Disease Patients in a Pediatric Hospital

PRINCIPAL INVESTIGATOR: Regina Prusinski

CONTACT TELEPHONE NUMBER: (614) 722-9429 or
regina.prusinski@nationwidechildrens.org

SUBJECT'S NAME: _____ **DATE OF BIRTH:** _____

NOTE: The words "you" and "your" are used in this consent form. These words refer to the study volunteer whether a child or an adult.

1) INTRODUCTION

We invite you to be in this research study. The nurses who are eligible to participate are permanent registered nursing staff with a minimum of 1 year experience working on the cardiology floor. Requisite knowledge, skills, attitudes, and resources for RNs caring for ACHD have not been previously defined or described from the perspective of the nurses. Information about requisite knowledge, skills, attitudes, and resources may be found in the stories of the RNs who provide care to ACHD without benefit of a formal training program.

Participation is voluntary. Using this form as a guide, we will explain the study to you. If you have any questions about the study, please ask. Once you understand this study, we will ask you to decide whether you would like to participate or not. By signing this form, you agree to be in this study. If you do not want to be involved with this study you have the right to choose not to participate. You have the right to leave this study at any time, even if you agree to join now.

2) WHY ARE WE DOING THIS RESEARCH STUDY?

Advances in medical treatment, management, diagnosis and surgical palliation have improved the quality and longevity of children born with Congenital Heart Disease. As these patients age, reach adulthood, and experience additional health problems, they continue to be seen within the pediatric medical settings. Nurses skilled in the care of children are increasingly

called upon to care for adult patients and their families. However, there are no data or guidelines available to provide direction to the preparation of pediatric registered nurses to care for adult patients with complex congenital heart problems. This is a study to find out the knowledge, skills, attitudes, and resources RNs perceive as necessary to care for adults with CHD at Nationwide Children's Hospital Heart Center.

3) WHERE WILL THE STUDY BE DONE AND HOW MANY SUBJECTS WILL TAKE PART?

This study will be done at Nationwide Children's Hospital and we hope to enroll 15 to 25 participants.

4) WHAT WILL HAPPEN DURING THE STUDY AND HOW LONG WILL IT LAST?

A group of nurses, 3-5 people, will be interviewed together in a private area near the cardiology floor. Light refreshments will be provided to participants. The focus group interview will be scheduled for a 1 hour time period with established questions to guide the exploration and discussion. A moderator and co-moderator will facilitate the focus groups. The moderator will ask the questions to the focus group while the co-moderator will record the questions and answers. The focus group interview will be recorded for dictation. The expected total time for the interview is 30 minutes to an hour.

You will not receive any money or other compensation for any new products that might be developed or sold from this research.

5) WHAT ARE THE RISKS OF BEING IN THIS STUDY?

We believe that there is very little chance that bad things will happen as a result of being in this study. It is possible that you could feel upset when answering questions about your experiences, but it may be more likely that you find the questions or feedback process a little boring. If you do find any of the questions upsetting or don't want to answer a question, you don't have to, and the study coordinator will be available to discuss this with you further.

There may be other risks of being in this research study that are not known at this time.

6) ARE THERE BENEFITS TO TAKING PART IN THIS STUDY?

Although there may be no benefit to you from being in this study, we hope to learn something that could help others.

7) WHAT HAPPENS IF BEING IN THIS STUDY CAUSES INJURIES?

We believe that there is very little chance that injuries will happen as a result of being in this study.

8) WHAT HAPPENS IF I DO NOT FINISH THIS STUDY?

It is your choice to be in this study. You may decide to stop being in this study at any time. If you stop being in the study, there will not be a penalty or loss of benefits to which you are otherwise entitled.

If at any time the Principal Investigator believes that this study is not good for you, the study staff will contact you about stopping. If the study instructions are not followed, participation in the study may also be stopped. If unexpected medical problems come up, the Principal Investigator may decide to stop your participation in the study.

If you are an employee of Nationwide Children's Hospital or the Research Institute at Nationwide Children's Hospital, your job or performance appraisal will not be affected in any way if you decline to participate or withdraw your consent to participate in this study.

If you are interested, the final study results will be shared with you once they are available. Please provide us with an email or address where we can send these results.

Nationwide Children's Hospital is a teaching hospital and we are committed to doing research. Doing research will enable us to learn and provide the best care for our patients and families. You may be asked to participate in other research studies in the future. You have the right to decide to participate or decline to participate in any future studies. We will not share your contact information with researchers outside Nationwide Children's Hospital.

9) HOW WILL MY STUDY INFORMATION BE KEPT PRIVATE

Information collected for this study may include information that can identify you. This is called "protected health information" or PHI. By agreeing to be in this study, you are giving

permission to Regina Prusinski and the study staff to collect, use, and disclose your PHI for this research study unless otherwise allowed by applicable laws. Information collected is the property of Regina Prusinski.

The reason why this PHI is collected, and what information will be used is listed below. The PHI will only be shared with the groups listed, but if you have a bad outcome or adverse event from being in this study, the Principal Investigator and staff or other health care providers may need to look at your entire medical records. In the event of any publication regarding this study, your identity will not be revealed.

The PHI collected or created under this research study will be used or disclosed as needed until the end of the study. The records of this study will be kept for an indefinite period of time and your authorization to use or disclose your PHI will not expire.

PHI that may be used or disclosed:

Names

Birth date

Length of hire

E-mail Addresses

People or Companies authorized to use, disclose, and receive PHI collected or created by this research study:

- PI and study staff
- The Nationwide Children's Hospital Institutional Review Board (the committee that reviews all human subject research)
- Nationwide Children's Hospital internal auditors
- The Office for Human Research Protections (OHRP) (the federal government office that oversees human subject research)
- OSU School of Nursing

Because of the need to give information to these people, absolute confidentiality cannot be guaranteed. Information given to these people may no longer be protected by federal privacy rules.

Reason(s) why the use or disclosure is being made:

The PHI used will be used to contact you, if needed, in the future.

You may decide not to authorize the use and disclosure of your PHI. However, if it is needed for this study, you will not be able to be in this study. If you agree to be in this study and later decide to withdraw your participation, you may withdraw your authorization to use your PHI. This request must be made in writing to the Principal Investigator at 3931 Boyer Ridge Dr. Canal Winchester, Ohio 43110. If you withdraw your authorization, no new PHI may be collected and the PHI already collected may not be used unless it has already been used or is needed to complete the study analysis and reports.

10) WHOM SHOULD I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about anything while on this study or you have been injured by the research, you may contact the Principal Investigator at 614-292-4989, Monday – Friday, between 0900-1600 or email regina.prusinski@nationwidechildrens.org.

If you have questions, concerns, or complaints about the research; if you have questions about your rights as a research volunteer; if you cannot reach the Principal Investigator; or if you want to call someone else - please call (614) 722-2708, Nationwide Children's Hospital Institutional Review Board, (IRB, the committee that reviews all research involving human subjects at Nationwide Children's Hospital).

Subject's Name _____ **Date of**
Birth _____

**SUBJECT or SUBJECT'S PARENT OR PERSON AUTHORIZED TO CONSENT ON BEHALF
OF THE CHILD (SUBJECT TO THE SUBJECT'S GENERAL MEDICAL CARE)**

I have read this consent form and I have had an opportunity to ask questions about this research study. These questions have been answered to my satisfaction. If I have more questions about participating in this study or a research-related injury, I may contact the Principal Investigator. By signing this consent form, I certify that all health information I have given is true and correct to the best of my knowledge.

I have been given a copy of the Nationwide Children's Hospital Notice of Privacy Practices. If allowed by law, I understand that my right to any information that is created or collected by Nationwide Children's Hospital for this study can be temporarily suspended if necessary for the purposes of this research project. I also understand that my right to access to this information from this study will be reinstated upon completion of this research unless I have been told by the Principal Investigator that I will not receive study results.

I agree to participate in this study or I give permission for my child to participate in this study. I will be given a copy of this consent form with all the signatures for my own records.

CONSENT SIGNATURES

SUBJECT or SUBJECT'S LEGAL REPRESENTATIVE

DATE & TIME AM/PM

PERSON OBTAINING CONSENT

DATE & TIME AM/PM

I certify that I have explained the research, its purposes,

and the procedures to the subject or the subject's legal

representatives before requesting their signatures.

Appendix F

Focus Group Interview Composite Questions

Question Composite #1

When you hear the words “adult congenital heart disease patient,” what comes to mind? Just first image?

Group 1

I just picture the patients we've had who had their heart repaired 20 years ago or 30 or—[slight chuckle] who usually are blue and clubbed, asidies and oxygen, I don't know [chuckle] That's what I think.

I agree [Giggle] I picture lucky people that are happy to still be alive. I think that's a good way of putting it. *And don't make it that long.*

Yeah

And usually when they come in, it seems—a lot of them are not going to be here much longer. [Chuckle].

We've had a couple though who looked pretty good.

Yeah

A guy in the back, I was surprised, he was—I don't know his name. [Giggle]

Just reached forty-five or something and what did he have done? Is it the valve or pacemaker or-- I don't know, just recently?

I mean, it's probably been two months.

Oh, sorry.

I'm like, just barely [giggle]

I don't know, they come and go so fast when they're there.

I also think a lot of them it seems like they're socially—like delays and maybe not as—I *wouldn't* say productive, but it seems like they just had some challenges.

Yeah

All of them still like seem like *they'll get home*, parents are always—

A lot of them--**[Overlap]

Parents are coming in and taking care of them and—not married.

Not married, yeah

OK, so we've decided cyanotic, blue, oxygen dependent usually, kind of decreased social skills and responsibilities.

Group 2

Something that comes to mind is compliance.

Oh, OK, I would never think of that.

I feel like a lot of times they come in, like an order comes in, and “Nope, that's not how I do that. I don't take that at that time. You know, you're supposed to take that at that time; I don't.”

[Chuckle] Or they're coming in because they haven't taken something.

That makes sense

Are there other things besides like medication adherence that strikes a chord with you when you think about the adult patient with—

Good or bad? Good or bad? Anything. I mean, I feel like my experiences have been pretty positive. When I get an assignment and I see that I have an adult, I don't go, "Ugh" at all. I don't know if it's just the congenital heart world, [but] I feel like they're all very pleasant. We all have our days and our moments, but it's not a bad assignment to get an adult. I kind of like. It's a nice change.

Anything else?

No. I'm the same way. They aren't hard.

Group 3

Just an adult that had a heart problem at birth. That's the only thing that comes to mind.

[Chuckling] They were born with a heart problem.

Any other impressions or reactions.

They've probably had several surgeries depending on what they were born with.

I don't have an initial impression just because they're adult, usually.

Group 4

A failing fontan

Asidies

Noncompliance

I'd say the asidies and the noncompliance

So when asidies are you thinking just "big belly"? Is that what come to mind?

Mm hm

Usually from their failed fontan

Some form with quality of life

We don't typically see them in our clinic visits. I mean, there's usually only here when they're sick. So that's usually when they—I mean, we get the few that have the valve replacements, but they kind of come in and go kind of thing. I guess I think more in the chronic people than just valve replacement in out.

Other impressions or thoughts?

I think that the adult team by rounding with us has moved mountains as far as their care up here when they round with the cardio team. And everybody understands the plan from the beginning, and it's consistent each day. That's made it a much more positive experience for the nurses to care for them.

I think when you hear you're getting an adult patient, everybody kind of cringes a little bit, but then once you start taking care of them, sometimes they can be your favorite patients, kind of thing. You think about it and you're like [Grumbling tone], "Oh, God, here comes another patient." But like you said about the one we have today, it's actually pleasant to take care of—He's wonderful

Question composite #2

How do you compare the adult congenital heart population and the pediatric congenital heart population to one another?

Group 1

I feel like the issues and complications that you're looking for are different cuz the adults have such long-lasting—you know, their livers are bad or their--

Other system?

Yeah, like it's kind of just—I guess you don't see stuff like that in the babies and even like our two year olds or whatever. They're blue, but [chuckle]—I mean sometimes, but—

Not quite the same

I look at *as similarity that* in the pediatric as well as the adult, they are still very dependent on their parents as their number one caregivers. Maybe delayed in certain ways too.

So you feel like they don't transition out of ever needing that extra care almost.

Very few

Yeah, I agree.

Yeah, I think so too.

I agree. [Giggle] Agreed!

Group 2

As far as care, I feel like—and I don't know if this is exactly what you're asking, but when you have kids, it's the parents that are on top of the disorder or the defect I should say, and then ideally, the adults are the ones that are in control of answering your questions, they know their plan of care—or they should know. So that's the difference. I'm not sure if that's what you're asking. I would say that as far as the adults, maybe because they're so far along, sometimes they do feel a little more sad than the kids because that—

They've usually accepted. They usually have the *palette of care* packet in the room or**[Overlap]

Right, and the colors, just even just the color looks bad. The kids, there's always that hope that the repair will bring a new lease on life. And then you see the 20-some year old, and you're like, "Oh, but it didn't really **."

We bought time

Yeah. That's maybe one thing I feel like it's a little *more down*. I enjoy caring for them; it's a little more sad for me I think.

Are there differences in what you see as the care needs? You talked about the dynamic of parent verses patient and alluded to some of who's controlling the knowledge or the actions, but in terms of your actual care delivery, have you noticed other differences in what you think you have to do or how you do care between adults and kids?

That's new to me, adults. I don't know what I'm trying to get at here. I'm thinking—

Example—badges. They just recently got an S badge for spouse. You would never have to hunt down and S badge for your three-month old.

And extractives

I think education, when you have a child that's often in the forefront of your mind, whenever you bring that into the room—not whenever, not every time, but you think, "Oh, this is something they need to learn about." Sometimes with the adults, I may care for them all day, and never have once thought, "Oh, I wonder if they needed any education." I just assume, probably more than I should assume but.

I feel like we fight the addiction a little bit more, like the pain med addiction with the older population. (Obviously, the younger ones don't have it yet), so we're like, "Do you really need this? Or do you just want this? Then you have to figure that out in your head ** I don't want [you] to be in pain, but we don't want to just *give it* around the clock for—

OK

Their cares are the same. I mean, you still deliver meds, you give meds still on time. You leave the grooming and that sort of thing a little more up to them. I'm not hounding them maybe as you would like a child, but the basics are all the same; you're still nursing both of them.

Group 3

I find with some of the adults, you have to be more straightforward of your expectations of getting up to the chair, taking their meds at the time that we give them to them. I feel like they can sometimes, not take advantage of us, but the need to be nursed as an adult just as much as a two year old would be and that ensuring that all their needs are met, they don't always take on their own activities of daily life as easily as you would think an adult would. Sometimes they require the same encouragement or push that a pediatric patient does. And I think sometimes that's where the nursing frustration comes in because you expect—sometimes I expect more from them because they're older and they're an adult and they can make their own choices. But it's frustrating when you have to encourage them to get out of bed, encourage them to drink fluid, where the pediatric population, I feel like you're holding them back a little bit to settle them down when they're not as—you know, they want to get up and move. Meds are a different story, but they're ready to eat as soon as you put anything in front of them or asking for more. So I wouldn't say it's completely different, my approach to nursing, but I think I've learned to make it the same because they need, I don't want to say unfortunately, but somewhat unfortunately, they need that same approach of direct expectations of their plan of care I guess. Does that make sense?

Mm hm

Yeah. I get that.

How about the others at the table?

Are we talking about both, the whole floor?

Anywhere. Anywhere adults verses a kid.

I think that there is a lack of understanding in the immediate post-op phase of what the adult needs. So that being said, the timeline of when they're expected to be up, which should be very quickly, the needs that they have as far as their verbal, they can tell you what's bothering them, and they keep thinking it's pain; they just go and get the pain medicine. And the person's ready to vomit, but he's intubated. Those kinds of things. Judging agitation on a patient who you might be able to ask, "What's wrong?" So that's a developmental thing, obviously. And I think every once in a while, we catch no matter what the— *balsazaar* is somebody who has ordered a dose that is weight based for an adult that doesn't need to be. So those kinds of important things.

And that sounds more like an experience than—

Sure. And it's not that you don't, but when 90% of your world is this world, that 10%, you don't remember that fine detail all the time in the busyness of the day.

I used the example of you have your cath patients that come up post-cath. Do you do anything different if somebody said, "You have a two year old coming up post cath. You have a 22 year old coming up post-cath." How would you prep different? How would you--?

I'd rather have a 22 year old post cath than a two year old post cath.

Mm hm

Mm hm

Cuz they can lay still and do what they're asked to do verses that type of patient.

The two year old you have to—I mean, you cater to the patient, but you also have to really involve the family more and getting them involved in helping us keep that patient calm and lying flat for the appropriate time. Where an adult, they love to come up and they sleep that first hour normally. [Chuckles] and then of course, they are asking to get up about four hours into their bed rest. So you have to—I would much rather have an adult catch than a—as long as they don't bleed. [chuckles] *The D test*. [chuckles]

Group 4

I usually find that they're more needing of pain medications
Meds, **

I think they're usually harder to get going afterwards. They don't seem to be as compliant as far as getting up and ambulating. They seem to regress more than a child would.
I feel like you have atelectasis more with the adults maybe than like the pediatric patient, just because of that.

Are there any other characteristics or needs or anything that you see as being unique to one end of the age range verses the other?

I don't know, I feel like maybe the adults might have depression as well because of everything that they've gone through compared to a child who hasn't yet had that much experience. They might be embarrassed to be at a pediatric hospital. I've heard an adult say that before. They feel like everyone looks at them when they're walking through the hall.

Question composite #3

Think back to one of the first times you took care of an adult congenital heart patient. What was that experience like?

Group 1

I'm going to be honest. I got into peds because I love peds. My first adult, I'm like, 'Mm. Why do we have adult congenital patients on our floor?' [Chuckles] Like, *I have a 53 year old*, whatever. But over time, I don't know. You just fall in love with everybody. It's true. They just want what everybody else wants: a quality of life. It is different with the compliance, and you think of the—I know**—but like the J-- L—s [Anonymous] of the world who are super mean. Then I still think, "They're just mean because they know they're dying." So you're fighting that—Don't take it personally but still try and bring them up out of it. I don't know. It's a harder path to walk down.

One of the first adults I had is actually here now, A-- B-- [Anonymous]. It's like ironic that he's here today, but he was one of the first people I had. Of course, he just comes with all kinds of funny stories. But still, [I] just kind of like want to shake him. Like, "Come on! Just do what you're supposed to do." And he's like, "I behave when I'm here anyway, so why do I need to behave?" And you're like, "Oh, well, because you're going to buy yourself some time." [Chuckles] And you love him cuz he's just so funny and loveable, but then you just get really frustrated.

Yeah, they just have to do what we say. [Chuckles] Like they have to!

Yeah

We're going to give you your med *and your tea too*.

And then if the parents don't do it, you're still frustrated, but it's not that patient. That's when it switches over the adults that you don't want anybody else to be frustrated at him or them. And at

least babies, you can still get your frustration to the adult in the situation but—I'm not sure what the question was but maybe I answered it. [Laughing]

Basically I just wanted to—

First experience, I remember now.

Hear about your first experience with adult congenital patients.

It comes coming to that compliance thing. I feel like that's so frustrating.

Group 2

R—M—[anonymous] was classic.

Oh!

Like she was dead [chuckle], like all the time.

Oh yeah

And that takes a while to get used to I guess if you haven't worked with adult congenital heart patients before. Like when do you worry about something when it's like she's had these problems forever, and now we're—is this a big change or normal? Yeah, I guess—

Did you feel like that's hard to get over? I don't know, get over the—you want to fix it, but you can't fix it, kind of?

Yeah

Yeah

What about you? First patient, do you remember?

I think my first one was J—L—[anonymous]. *You'll* agree with this. He was literally the color of my pants, and that was his base *line*.

***Very clamped [Overlap]*

He was also an extremely classic patient.

Yeah

I don't remember him.

Like, this is what you look like at home?

[Chuckle]

It was definitely a shock.

Mine was R—M—[anonymous] also.

One thing I just think differently—they're just very needy.

Yeah ***[overlap]*

Very needy.

Yeah

I know with J--, he just would call out for anything because he liked the attention. He didn't like being alone in the room.

Yeah, they're socially isolated.

It might be because the babies don't know how to use call lights either. [Laughter]

That's true

***[Overlap]*

We just *blame it all on* [overlap]

We're just not used to it

Maybe holler for you specifically.

I know, I mean, yeah. So that could be just part of it is you get used to dealing with a certain population that— a lot of our babies don't have parents here necessarily—

Yeah, that's true.

--so they don't call out. They cry, we go in, but it's not like they're calling out for pain meds or juice or repositioning or—

** [overlap] adult world, and we just don't ** [Laughing]

I'm from OSU. And that is the real adult world.

Is it?

Oh yeah. They *don't have to call out* for anything. They call you for everything.

Group 3

Overwhelming. I don't know if it counts, but it was a —well, I think my first adult was actually a transplant, so that involves much more. And I was still in orientation or just out of orientation, so of course it's a lot of meds and a lot of cares, but she had a congenital history so she had been in-patient quite a bit, so she knew the system and stuff. And I felt like I learned a lot from her because she was pretty involved in her care and her needs and her own expectations, but I was overwhelmed.

The first one I can remember was an end of life. I can't think of her name. It was one of Dr. K—'s patients. She came in because she didn't want to die at home; she wanted to die here. And she had come in I think several times before that, but it was basically a failing kind of thing. We ended up taking her off *telemetry* and off of everything. And she just **[Intercom interruption]. And that was kind of a whole new experience, like coming to pediatrics you don't think about end of life, you know what I mean, necessarily right away or whatever and having to deal with—I mean, we're doing fentanyl patches and all that kind of stuff, but—it was kind of an eye opening experience I guess.

I agree with both, like overwhelming and eye opening. Just quality of life, just to see how their life differs so much than say from myself, an adult with something.

Eye opening to what they're doing and how they're living at home and meds and everything that they do.

One of the other ones I can think of taking care of early on was J—L—[anonymous] who was opposite of the girl that died. She died not because she wasn't noncompliant, where he, any time anybody ever heard his name, everybody dreaded taking care of him because he was whiny, he was demanding, he was noncompliant. But then as you took care of him he kind of grew on you. There were some people that couldn't stand to take care of him, but there were others that didn't mind.

You really had to assist him with ADLs. And that was frustrating sometimes because you knew he was quite capable.

Right. And it was more that he was capable. He just wanted you to do it for him.

So manipulation

Yes

Yeah

And demanding; he was very demanding when he came here. And I think, my opinion is, it came from past experience, throughout his teenage years he was kind of waited on, treated as a person with a disability. [It] enabled him to be that way.

That's another frustrating part about taking care of some of our adult patients is that I feel like they're so enabled by their families. And I don't know how I would parent a child with a defect or a terrible congenital disease, but I feel like sometimes the families are what are suppressing their development and their growth. And that is frustrating as the nurse to care for that family

where, you know, if that mother or father did not enable them as much that they would be making better strides.

More self-sufficient

Or getting out of bed to the chair because the dynamics often change when a family member leaves the room—even if it's for a short period of time. I feel like sometimes they hold them back.

And I don't know if that was just the mindset back in those days. I'm sure they probably told them they were going to have no quality of life; they're not going to live.

Right

Those kind of things, so I mean, like she said, as a parent I guess you would do that just because you don't know how long you have.

Yeah, they're not looking long term.

Right.

This is kind of off-script, but do you think that's changed? That parental perspective?

I think some here and there. I try to promote it. I try to encourage families not to treat their child as a disabled child. Those are even words that I say to them, "Treat her like a normal baby. Treat her like—do all the things you would with your other kids." Those kind of things. I think we're more educated to tell them those things, whereas back then I don't know that they were ever told those things. Now there are still some parents that don't listen to us per se, but I think that we are more educated to tell them that "It's OK; they can be like your other kids."

I think it depends on the parents too a lot.

Mm hm

But I think it's definitely different than back then.

I agree. I definitely agree. We have some pediatric patients that I know we're going to see as adult, or hope to see adults. And their families tend to let them get away with a lot of things that you wouldn't let—they don't let their healthy siblings get away with. And we all kind of talk about dreading their readmissions in the future because they're going to be rather needy patients or noncompliant patients and expect us as medical staff to be able to make positive changes in their medical care plan when had they been more compliant or not as restricted or more regimented then maybe they wouldn't need medical needs as soon as they do.

Kind of like you're going to be put in the place where you'll be the "bad cop"?

Yes. That's a good way to put it.

And you're called that. [Chuckles]

Other insights, thoughts?

I don't think it helps that if you don't have a lot of experience with the adult population that pediatric nurses aren't prepared for it either. And so when they do get this really tough patient, they have to struggle through getting them to respond to them the way they need them to so that they can get their workflow done and that kind of stuff. And they are difficult. They can be, especially if they've been chronically ill and handicapped by the family.

I think **[Overlap]

They're just as much behavioral as they are anything else. And then you have this big person that's behavioral verses a toddler. [chuckle]

Yeah, and I feel as a nurse you're spending a lot of that time meeting the emotional needs of that family or that patient, where your two month old patient neighbor needs medical needs met or nursing needs met, and you're spending more time as you would like as the nurse dealing with

emotional/psychological needs than nursing or medical needs. And it's all about workflow and understanding that they need the same amount of time as pediatric patient population.

When I think, on R---'s comment too about nursing—and I think you almost have to be an assertive nurse to get your point across to them because if not, they and the family will walk all over you, kind of thing.

Very assertive.

Yeah. You have to be confident in your skills and what you're doing.

And as a charge nurse, you keep that in mind when you're assigning these patients, especially those "frequent flyers" if you will. If we have a passive nurse, we'll try to give it to the more aggressive nurse or the more experienced nurse just because we know that will be easier for all nurses involved and the patient really.

Group 4

My first experience wasn't very good. [Chuckle]

Mine either.

Cuz I had a patient that they could get up. They had a bedside commode but basically refused to do it. So I went through a day of—I had to change their bed like eight times in one day because she refused to get up and go to the bathroom. And her spouse was even there, and he wouldn't help me either. [Chuckle] So it was a bad situation. I mean, that was not a common situation, but that was my first experience.

One of the patients I can remember, he was waiting on a heart for a long time, so it was just really sad because he was bored and he knows what's going on, knows that he's like stuck in the hospital waiting on a heart. It just seems really sad.

Hell, we all know. [Laughing]

We all know.

That was a challenging experience for everybody.

****it's hard when it doesn't go so well**

Yeah

You've alluded to some, but are there other challenges or difficulties in taking care of adult congenital heart patients in a pediatric setting?

We've used the example of like a really tall man and the beds aren't long enough. Or they want to use the phone to call home, and you don't have a phone they can get to because they're in the bed.

Maybe they like want to go downstairs to the cafeteria, and when they're on our monitors you can't really do that. And I think they want to do something more than like—a child doesn't really ask for it, doesn't know to ask to leave.

And as an adult, a lot of times they'll have more people who want to come see them. They're not able to come cuz there's only so many—it seems like the adult population, they have a lot more people who could be involved to come see them. And you are right, they do like to get up and leave the floor a lot more often. And we're not always able to accommodate that all the time.

Question composite #4

So what are the challenges or difficulties in taking care of an adult congenital heart patient in a pediatric facility?

Group 1

Do you have any examples?

I have an example to start people. So if you noticed, a couple years ago we didn't have a spouse sticker. So we'd have all these adults come in that were married. We had a few that were married at the time that were returners, and their spouse would have to work like P for parent. And I found it really like derogatory. And it just recently got fixed. So I was trying to think of the different things we run into.

I don't like it that we— there has been some little ** patients we've gotten here who are engaged or have significant others who are not allowed up after visiting hours. What? It's their fiancée. It's like, "Nope. The rules are same for everyone. Only parents and grandparents during—" Which a lot of the adult patients do get upset about it, which I can understand.

I had no idea that was even the case.

Yeah, it's terrible.

We still have to treat them just like they're pediatric patients.

That's ridiculous.

You can only come up after visiting hours if you are indeed a spouse.

Oh, I had no idea.

I had no idea, yeah.

That's sad.

Think of any examples?

I guess I would just—I can't think of something super specific, but just things you're not used to. I mean, issues that you don't normally take care of, and you—

You mean like in relation to adults? Like that just the child you're taking care of as an adult congenital?

Yeah, I mean, she had that peritoneal drain that I guess some kids probably have that, but not our babies that we take care of normally so—

Different equipment

Yeah. Just like it's all new to me. But I mean, that happens with lots of different patients I guess, but I can't think of a specific example.

That's OK

I think *going off the unit is an issue--*

Oh, that's—yeah

--because they want to go down to Subway or the cafeteria to eat or whatever and you're like, "No," And then the doctors change it to --it's supposed to be universal across the board. Now they're not supposed if they're *on telemetry*. And then doctors will change it for this specific patient—Oh, they're a frequent flyer and they can go down. And that's been a huge issue of them not being able to leave the floor. We hold them to the kids' standards of--you can't— Right. You can't take care of yourself.

--You can't take care of yourself. And then we get super angry when they don't take care of themselves.

Can I get an example of the patient, to see what their ** are?

What was the name of the 22-year old that passed?

Oh, she was the one that wanted to leave the unit and **[Overlap] Easter
Right.

Yeah

And got drugs and—

Yeah

**[Overlap] Are you talking about D--?

Yeah

And that's why I'm sure that's when they came and started cracking down on it.

So what are the difficulties in caring for her? I can imagine as a nurse it's got to be—

I had a **

But then you have her brother and people who are doing the *drugs*. They can bring it up to her just as easily as she can go down and get it.

Oh yeah, you do have to treat them different, though. I mean, they're an adult and they make their own decisions—

They're an adult, absolutely

--and if she wants to do that, that's her choice

Right

Right

Yeah, exactly

We can't control that. I mean, yeah, we should have protocols and they shouldn't be able to leave the floor with a central line to go do—

Do drugs, right

I do think that's an issue we run into. They came down to Subway, cafeteria, down to get pizza.

That happened what? Just a couple weeks ago. They went down to get pizza.

Well, S---[anonymous] was allowed to leave the floor, and I had to sign something saying—I mean, she had chest tubes so she was responsible of taking care of that if something happened.

Like you said, she was an independent person that was here for a long time. You can't very well tell her that she has to take a nurse with her every time she wants to go anywhere.

Yeah, when they're really restricted -- ***we can't go*

So do you guys get a physician's order that says it's OK for them to leave the room? Or go downstairs? Is that how it works?

Yes. The physician says—

Sometimes we get patients where it specifically has orders that patient cannot leave.

Cannot, OK.

Which is also the rule, but it doesn't always—sometimes they have an order reinforcing that.

So challenges and difficulties we talked about is their independence pretty much and the rules and regulations that we have in the hospital are not designed for these adults. Sound good?

Group 2

Frustration. I feel like they get frustrated.

I think of G--- B---[Anonymous] immediately. Here for nine months, 6 til 6.

Babies will cry

Yeah, babies are crying and everything is based around kids, and he's *** like beds too small, everything.*

Yeah, like I had an adult today, and I was in his room, and the baby next door is crying. He or she's been crying for a while, and I actually thought about that in his room. "What must he think about that?" Like hearing—and he's been here for months—hearing babies cry all the time.

That's not your baby, you know? It's hard enough to hear your own baby cry.

Right. H—[Anonymous] comes around, he's like, "No, I don't want to paint a unicorn. I'm 36 years old." [Chuckle]

Yeah. And I feel like we as staff try to—

We do

--humanize it or make it more adult-like, and we try to keep the conversation **[Overlap]

I never thought it would be—I don't know if I would like to be here for months as an adult, in a children's hospital.

Yeah, I think a short stay would be like, uh, whatever, but those long extended stays would be frustrating. But I'm assuming that. I can't say I heard a lot of people complain about it.

And I know a lot of us are pediatrics because we like pediatrics, and so a lot of nurses don't want the adults either so I don't know if it wears off in their presentation/attitude. I'm sure their care is the same, but like —

You never know—

**[Overlap] "Oh, they're so cute." *Adults are like, "Really?"* [Chuckle] *We're good*

Group 3

The segue off of it is, when they describe it, the child developmentally, just wants to be well enough to get up and play. The child has no concept of "I'm going to die in a couple months." The child has no concept of "I don't have enough money. I don't have health insurance. I don't have, I don't have, I don't have—for me"—if that's the way it is, depending. And then the adult has all of that worry. And/or "I'm 25 years old, but I don't have the same social life as anybody who's normal." And they're depressed over it. And that's difficult to walk into all the time too. So it's like they need another focus to go with their care I think than just the routine medical piece of it because that's what it is—that's the reality of where they are, whether we really want to look at it that way or not. And I think the other thing is is we don't—it's hard for us to deal with period, is that we don't want to ** either. It goes into a lot of that stuff. You have to—

** [Overlap]

--certain personalities, yeah. On top of ** *again*, you know.

So different sets of stressors probably need to be addressed, probably addressing of the new mom when the patient is the baby and getting them started verses the older patient, and they need a whole different set of stuff.

Question 5 Composit

Next question: Do you think there is a specific knowledge base or attitudes or aptitudes that you think are really essential to caring for an adult congenital patients in a pediatric setting—or even just comparing taking care of kids or taking care of adults? Is there something that is—

That you would teach your orientee? And then the corollary to that, are there specific skills or resources that you think are essential to caring for adults compared to kids?

Group 1

Like maybe know that they have their own independence too. Let them do things that they're able to do, like their medications. Just give them more leeway I guess. They're taking care of themselves at home, so we have to make sure that they're able to do that too.

I don't have any thoughts on that. [Laughing]

That's OK.

I mean, they always present different symptoms than a child does. I mean, it just seems like when it's an adult, we're dealing with asidies and—it just is a total different situation usually. It always seems to be the same thing. It's a failing fontan, asidies, you know. *Direse and tap* and send them home until the next week they come back.

I don't know of any skills. Just maybe we let them know that they—like social work would be big with an adult patient I think.

So using your resources

That we have on the floor, like social worker, insurance problems. I know it's really different when they use their own insurance than their parents.

I know a previous interview brought up medications being a particular difference.

Mm hm

Oh sure

It's not like weight based or whatever maybe. [Whispering] I'm not very creative.

Group 2

Are there any skills particular to the adult patient groups? Like—I don't normally, might not put a PIV in a baby, but I'm good at putting a PIV in a 20-year old.

Well, I can do that. [Laughter]

Much easier **[overlap]

That's a skill

It is much easier. ** [Overlap]

*Germ and stuff like that. Being a ** bejesus out of you. It's fine.*

For labs, you mean?

For labs, yeah.

So you'd rather venipuncture than—

Oh, absolutely. I'd rather venipuncture the babies. I think you all need to learn how to learn how to do that.

[Laughter]

Yeah, I agree with you 110%. That's a skill that nurses have lost.

I think it's so much easier than trying to—

Or assessment skills. They're definitely different assessments for an adult verses a baby.

I don't think you have to do as much necessarily because you can sit there and look at them, and they can tell you.

They can tell you. **[Overlap]

That's true. I agree

I don't think your *assessment* skills have to be nearly as sharp.

They can tell you when something's wrong. I mean, they still should be sharp. [Laughter] *It's not as much **work.*

So summarizing, we think communication definitely is different with them. Skills might be a little easier in some things, but others might be a little harder.

[RECORDING ENDS HERE]

Group 3

Kind of what we said, to be assertive, direct, and open with the expectations of the day, whether it be the goal of getting to the chair or doing your *incentives* barometer, because that's always a fun nursing task. And I would tell that to the new orientee, and I also would mention that the psychological piece and the emotional piece, that it plays a bigger part than you anticipate and to expect that.

I would say assertive and being flexible and knowing that when you walk in that room, you're probably not going to be there for 15 minutes; it's going to be more like a half hour because it's the social aspect. I think a lot of times they just want to talk. And so if I have one, I know I'm going to leave that to be my last patient so I can go and just kind of sit and be like, OK *let's sit for a while*. [chuckle] so I know that.

We let them sleep in.

Mm hm

Their 8 a.m. meds, we –

Push more towards 9.

Push more towards 9, or pick as your last patient that you see as long as other needs don't need to be met. We'll save it for the end for that reason of spending more time with them and also allowing them to sleep—because they don't get up at 8 a.m. and take their meds at home.

You know what I hear is—and I witnessed it—if you talk to the neonatal nurses and they're truthful about some things, they'll tell you the reason why they love—cuz that's probably the unit that has the most tenure. It doesn't matter what hospital I've been in, they've got 25 year tenure. And one of the factors is is they can totally control the patient.

And that is the personality of the NICU nurse

Yeah, and it is [laughter], verses you know that with the peds, you can do some control because you're it, but when you get into the older age range, you don't have as much control in your work day.

Not at all

No

Any other thoughts about specific—is there any unique knowledge?

I think knowing what a –I mean, I come back to the failed fontan—like not even knowing what their true diagnosis is, but you can think, as soon as here the asidies and you have a picture in your mind of what they're going to look like and you think about, “They're going to ivy lasiks; they're going to get diuretics, as many diuretics as they can.” I guess I think more of like congestive heart failure on that end of adult world kind of thing is what you're treating. So as far as the knowledge, congestive heart failure in a child or infant looks a lot different than congestive heart failure in an adult. They're just more uncomfortable. I think about what we learn: congestive heart failure in an infant, you're looking for *tikipnea*, *borfeney*, all those kinds of things, [those] kind of get grilled in you. Whereas this patient just doesn't feel well and their belly's big. So it's a different kind of mindset where you're treating the same thing.

And I think also just keeping in mind—I can't remember how long ago it was, but we had a little educational in-service on the adult congenital patients, and it was a friendly reminder that they are adults like us and they have needs like adults do and most of them want to have a job, want to have a relationship with somebody, they want to have activities outside of their job. When I see

them or saw them, I saw them as a patient, not as necessarily an adult—I mean, you see them as an adult, but you don't see them as an adult outside of the hospital.

A functioning adult

A functioning adult

A real person

Yeah. And wanting to go to the gym and workout or wanting to take their dogs for a walk and have kids. And you forget about that stuff. And it was, I think, one of your in-services with J— [anonymous] that really brought that to light for me. And I think the education was really important in caring for these adults.

The flipside of that is—are there any specific skills or skillsets that are unique to the adult as contrasted to the child?

Or resources that you have to rely on to get those skills or they have skills needed?

I rely on pharmacy because there are a lot of meds I don't know.

They're comorbidities.

They're comorbidities.

In the acute phase, again,--and this isn't going to be fontan, but this is going to be, a kid comes in with congenital *restenosis*, and has been watched. So now he's 30. And they're letting you *TAC* away post-op thinking that that's a good thing because all the infants have to *TAC* away in order to have cardiac output; in fact, we're stressing that. And nobody gets that until somebody from the adult world says, "Well, ** on that. Turn it down." Whatever it is, or he's too dry, or whatever it is. They can't quite fine tune that. And I don't think that's a fault of anyone. I just think that we don't see them enough and then you can't log that in. But it's stress. It's a stress to the body. So those kinds of things bug me because we could tune that up more. The DVT, you know, prioritizing--Oh yeah. Get something going or get them moving because they can *throw* ** much easier. Just in post-op; I don't mean the kids that are complex like *glands* and stuff we're already covering but general post-op care for a cardiac patient that isn't twisted inside out. The same care isn't being offered. On this side, I believe it probably is, but you've got them by that point where you know the routine and they're already up and you got that down—

Right

-- I think it's the other side that suffers from that.

I think we do get to the point too sometimes where the tachycardian —and it kind of sometimes goes to the waist side when something else is really going on—

They're not supposed to be 130 all the time [laugh]

They're not thinking, yeah

No, it's supposed to be 80-100, come on.

And they're either hypertensive—hypo or hypertensive, and it's—Is that their baseline? Is that not their baseline? They're all on Norvasc or any other —

And what's making them feel good verses bad?

Right

You can't tell if they're just down because they're in the hospital or they don't have enough blood pressure!

Yeah, that's what I was thinking is the depression is the sleep all day or the hypotensive can't move sleep all day.

Right

So it's identifying those—or it is a skill to understand their parameters and see them differently than you do the pediatric population. I'm trying to think of other skills. Even the simple skills of

venipuncture and putting in a peripheral. Taking care of the congenital heart population, you're in that mindset the their profusion is not always great or they have been poked or prodded their entire lives and so you sometimes immediately look to the skilled IV nurses, and you're calling them right off the bat. And a lot of these patients would like that, and that's fine, but you forget that you occasionally will get a patient who has an *anacute* vein that's just as good as your own, and there's no reason that you would need to rely on somebody else's skills. It's your own nursing skill that you can carry out.

Group 4

I've never thought of it like that, honestly. I don't know.

The only thing that comes to mind—and she already said it—kids have to do, as far as meds, you go in, especially if they have an NG tube or N—and they could be sleeping through the entire thing.

You have to get a rapport with the adults.

Yeah. It's not like you can just go in and be like, "Here's your Lasix; here's your—

Defibrillator **[Overlap]

-- I mean, you can, but they're going to put a wall up. I feel like you [need to say,] "How do you like these pills? Do you want these separated?" Things that just take a lot longer than if you're just giving those three oral meds that baby. There's definitely more communication skills. But then in a different way—cuz you have to communicate—they're just a different set of skills. Maybe I'm just **, I don't know. A lot of them are dying or know they're going to die and so you have to very carefully tread that with them. Some of them don't want to hear about how to **; some of them do. Some of them don't want to hear the end-of-life stuff; some do. So you can't walk in and be like, "Hey! I have this packet for you." And they're like, "What? I'm not dying. What are you talking about?"

Maybe examples of when you get a post cath. I know the come here regularly. Do you do different things for an admission of a post cath that's adult verses a baby?

I don't think so. I mean, the bed rest for an adult is you're best rest until 7 o'clock, or whatever the time. And then for a kid, it's whatever technique we can get to keep this kid on bed rest for 4 hours or 6 hours.

And parents can hold the babies **[Overlap]

But I, as far as our admission process, there's really nothing different. Different profiles but the questions are really the same. I feel like you just go off cues. You just know if they want to talk now or give them a little bit of time.

And you've sort of incorporated but also any specific skills our resources that you think are essential to caring for the adults compared to the children?

***ed day is coming up.* I'm trying to think if we go over stuff on our *ed day*, like the difference.

But it's been a year since I've been in our *ed day* [chuckle], so I'm trying to think about it.

I think I rely on the doctors a lot to talk to adult patients.

Like the cardiologist specifically?

Yeah, because sometimes their questions can be a lot more—because shoot, they know a lot more about their condition than I do. So when they start having hard-hitting questions where maybe if it's a parent that's just starting to sort through, we can get through those steps together. But sometimes the adult patients just go right to whatever the question is. So I feel like I'll bring the doctors a lot more to talk—plus, I feel like they do want to deal with the doctor cuz they're an adult. Like they don't need that middle man all the time. I feel like they feel like they're a

little more respected if the doctor just comes and says, "This is why we're changing this order. This is why we're doing this." I assume a lot of things maybe. [chuckle]

Anything different?

No. I don't have a huge separation in my head. I'm just trying to think about it—I really don't. I think instead of focusing on parents, and if they're OK, you just focus on the patient and they're OK when it's an adult. When it's a baby, your parents, OK, I got the baby's care, but the parents, OK brain, thinking emotionally, whatever. When you have an adult—are they OK emotionally ** and stuff like that. So I just transfer it from parent to patient.

So your focus kind of gets consolidated.

Yeah

That instead of having 2 patients—

Right

Yeah

It's all rolled into one body here.

Right

Summary and additions

Kind of like a sum up, this is what I'm hearing from everybody in general, is that when we think of the adult congenital patient, we see the chronic noncompliant failed fontan image in our minds. Initially, there may be that—"I don't particularly want to take care of that patient." But actually, when you do take care of them you can get a very pleasant, positive experience. And that over time you've actually managed to make your own little niche where you've learned how to be assertive, *profunctual* nurse, and can work well with them. You've become frustrated because they're at times demanding and manipulative and you've been set up for failure because of ongoing developmental issues and families that don't set them up to be appropriate adults. And I think all of you would like to learn or move toward being even better at taking care of the patients because you all seem to have that underlying—you'd like to do the best you can for them. And then I did get a bit [of]—if you lack the experience of working with them or you lack that confidence in your own nursing care and that knowledge62 pathophysiology can lead to problems.

Group 1

Any other thoughts that either of you would like to share things we haven't asked about?

I don't think so

I don't find it difficult to deal with both sides, personally.

Why do you think that? If you think other people do have a problem?

I've never known that they did have a problem.

Then there you go. That's kind of what I was asking.

Yeah. I mean, I've never known anybody to have a problem *diff ** to the two*. Adults are probably easier to take care of other than you have to deal with their—they're kind of set in their ways and they have ways that they like things done. Just doing it though, you do what you got to do.

I guess their home compliance is the biggest issue it seems like with adults. And with kids we depend on their parents to do everything.

Cuz there are certain things that adults are easier. They can communicate with you and let you know what they do need. Sometimes it's a guessing game with the younger ones.

Yeah

Maybe that's why I feel like sometimes they're more needy. Maybe they're more needy because they can tell me what they need.

I like taking care of adults too. Different conversations I guess. [Laughing]

I can talk sports with somebody. [Laughing] When I come in the room, they usually have Sports Center or the game on. [Laughing]

Right. Just need male patients for him. So summary, this is what I'm hearing from both of you, and cut in if you think you want to add something or what I'm saying isn't exactly what you meant. The adult congenital patient, when you think of them is really just an adult who had a heart problem when were born, and they've probably gone through a couple surgeries or had other issues in their life that's brought them here. You don't see them as a particular problem to take care of, but you do see them as usually having more compliance issues, more pain problems, and maybe have more awareness of their situation. So it can be a sad situation. They can be depressed. It can be sad for the nurses. So both sides of that. Your first experiences don't sound like they were very positive, but it doesn't sound like it's foreshadowed your future experiences; they've been fairly positive, how you guys have taken care of those patients and liked it. You'd like to give them more independence and set them up so they can take care of themselves, especially when they go home. And it seems like those are some of things that could be improved upon, getting them a more home-like environment here and able to be more independent and self-caring. Does that kind of cover it?

Yeah

Yeah

Is there anything else you'd like to add?

We're just not being talkers

Yeah, sorry [Chuckle]

No, that's OK!

[Laughter]

That sums it up.

Group 2

So summarizing, we think communication definitely is different with them. Skills might be a little easier in some things, but others might be a little harder.

Group 3

Absolutely

Yes

And I think furthermore, we understand the interventions that this hospital in particular is doing and completely. We are going to be seeing a jump in the adult population. Now I feel like we see a lot of the ones that maybe were on the lucky side, and we'll be seeing a lot more adult with congenital heart defects. And they're going to come here, and so we need to be prepared. So I think just understanding that and excepting that is a step in itself.

Anybody else want to add?

No, I just know that—cuz I live over here—that even though they've had their struggles with them, they worry about them every bit as much, especially when you're watching somebody get *tacked* constantly. Some of that *end stage* stuff is really ugly to deal with.

Yeah

Just talking with the two groups I can tell everybody really cares about their patients.

Yeah

It's obvious.

When they're here for such long periods of time, you become their fam—I mean,

Yeah, they really depend on you.

Like G—J—[anonymous]. We were his family; he didn't really have a whole lot of other family. I know I didn't want to take care of him at all. And I did the day he got his transplant. We went to cath lab first, and he held my hand a little bit longer, and he said, "I'll see you in a little bit." I just like walked away, staring tearing up. I was like, "This is why I did not want to care for him!" [Laughter] This is why because he—he is a hu—

Because I guess the babies and stuff, you may make the emotional tie, but it's usually more with the parents verses the patient, whereas with the adults, you definitely make more of the relationship with the patient.

Yeah

Group 4

So mainly I was just going to say if you had one sentence that was the key thing that you heard from this little moment, like you were like, "Oh, that's what I got out of this." That's OK if you didn't.

I always wondered—and I think it's cuz I took care of him so long—how to make an adult feel more comfortable in a pediatric setting. How to make it OK for them to be here for nine months and not feel like, "Oh, my gosh, I'm an adult in a child's world."

Yeah, kind of the same, and if you ended up getting input from them that you can give back to us, that would be—

Yeah

That's good input alone. And then summary of the discussion, was there anything that would've liked to have discussed that we didn't? And what I got from what you guys talked about was that you have overall positive experiences taking care of adults.

Mm

Hm